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Published in:
HIV Medicine

DOI:
10.1111/hiv.12599

Publication date:
2018

Document Version
Author accepted manuscript

Monitoring response to hepatitis B and C in EU/EEA: testing policies, availability of data on care cascade and chronic viral hepatitis-related mortality – results from two surveys (2016)

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Objectives

The World Health Organization (WHO) developed a European Regional Action Plan (EAP) to fasttrack action towards the goal of eliminating viral hepatitis. Robust monitoring is essential to assess national programme performance. The purpose of this study was to assess the availability of selected monitoring data sources in European Union/European Economic Area (EU/EEA) Member States (MS).

Methods

Availability of data sources at EU/EEA level was assessed using two surveys distributed to 31 EU/EEA MS in 2016. The two surveys covered (A) availability of policy documents on testing; testing practices and monitoring; monitoring of diagnosis and treatment initiation, and; (B) availability of data on mortality attributable to chronic viral hepatitis.

Results

Just over two-thirds of EU/EEA MS responded to the surveys. 86% (18/21) reported national testing guidance covering HBV, and 81% (17/21) covering HCV; while 33% (7/21) and 38% (8/21) of countries, respectively, monitored the number of tests performed. 71% (15/21) of countries monitored the number of chronic HBV cases diagnosed and 33% (7/21) the number of people treated. Corresponding figures for HCV were 48% (10/21) and 57% (12/21). 27% (6/22) of countries reported availability of data on mortality attributable to chronic viral hepatitis.

Conclusions

The results of this study suggest that sources of information in EU/EEA Member States to monitor the progress towards the EAP milestones and targets related to viral hepatitis diagnosis, cascade of care and attributable mortality are limited. Our analysis should raise awareness among EU/EEA policy makers and stimulate higher prioritisation of efforts to improve the monitoring of national viral hepatitis programmes.

Keywords: European Union, indicators, monitoring, viral hepatitis

Introduction

Hepatitis B and C viruses (HBV, HCV) are associated with a large burden of disease in the EU/EEA, with an overall HBV prevalence of 0.9% and HCV prevalence of 1.1%, corresponding to an estimated 4.7 and 5.6 millions of cases, respectively [1]. Population groups with higher prevalence of HBV and HCV infection in the EU/EEA include people who inject drugs (PWID), people in prison, persons who have undergone unsafe medical procedures, migrants from countries with higher prevalence, men who have sex with men (MSM) [1–3]. Viral hepatitis disproportionately impacts upon the most socioeconomically deprived populations, and contributes to health inequalities in Europe [4].

The adoption of the World Health Organization's (WHO) Global Health Sector Strategy on viral hepatitis includes ambitious goals and targets to eliminate viral hepatitis as a public health threat by 2030 [5]. The Global Strategy was followed by the development and adoption of the WHO European Regional Action Plan (EAP) [4,5]. Robust monitoring is essential to assess national programme performance, including service delivery, and to inform policy development. To guide action in this area, WHO has developed a comprehensive and practical monitoring and evaluation framework to provide support to countries in monitoring their responses to the elimination of viral hepatitis [6]. The framework includes indicators that can be used by countries to monitor progress towards the goals and targets outlined in the Global Health Sector Strategy and the EAP. It is likely that additional indicators specific to the region targets may also be needed to monitor progress towards all the interim milestones and targets defined in the EAP. The EAP proposes a number of milestones and targets encompassing viral hepatitis surveillance, evidence-based policy and awareness, immunization and prevention of mother-to-child transmission of HBV, blood safety and facility-level injection safety, prevention of sexual and injecting-related transmission, testing for viral hepatitis infection and cascade of care [4]. The purpose of this study was to assess the availability of key sources of data in EU/EEA Member States in relation to selected EAP milestones and targets, namely: testing policies and practices, viral hepatitis care cascade and chronic viral hepatitis-related mortality; to understand the level of support that may be needed to help countries in monitoring their responses.

Methods

This study assessed the availability of data on testing policies and practices, viral hepatitis care cascade and chronic viral hepatitis-related mortality, using two surveys of EU/EEA Member States (MS) [7]. Due to the need to contain the size of the survey questions, only a sub-set of EAP milestones and targets were covered. This sub-set was selected considering the relevance for the European setting and based on the available information at the time of the design of the study protocol, which predated the release of the WHO EAP [4]. The two surveys covered (A) availability of guidelines and policy documents on testing; testing practices and monitoring; monitoring of diagnosis and treatment initiation, and; (B) availability of data on mortality attributable to HBV/HCV. For survey A, 'dedicated' testing guidance was defined as a guidance/policy document where the primary topic was hepatitis, and that testing was the main, or formed a component, of it. Survey B asked countries whether mortality data were available, rather than specifically monitored. Both surveys were designed

in electronic format to allow respondents to complete their answers on screen and submit responses by email. Surveys were distributed to the official ECDC National Focal Points for Viral Hepatitis [8], with up to three contacts made: a group invitation, and two individualised reminders. Surveys were distributed via email in March 2016, with reminder emails sent during April–May 2016.

Results

Survey results

There were 21 individual responses to survey A, and 22 individual responses to survey B. The UK provided two separate responses for each survey; one from England & Wales, and one from Scotland. Therefore, the response rate was 20 (65%) out of 31 MS for survey A, and 21 (68%) out of 31 MS for survey B. Survey results are reported by country rather than MS, due to the different responses from the separate UK countries. Responses to survey A and survey B were received from the following MS: Belgium, Bulgaria, Croatia, Denmark, Estonia, France, Germany, Hungary, Ireland, Italy, Latvia, Lithuania, Malta, Netherlands, Norway, Poland, Romania, Slovenia (survey B only), Spain, Sweden, and the UK.

Testing policies and practices

Eighteen out of 21 countries responding to survey A (86%) reported having national testing guidance covering HBV, of which six had dedicated HBV guidance. Seventeen (81%) had national testing guidance covering HCV, of which 10 had dedicated HCV guidance. Thirteen countries (62%) had HBV/HCV testing guidance covering PWID. Six (29%) countries had HBV testing guidance for MSM and four (19%) had HCV testing guidance for MSM. Eight countries (38%) reported that routine HBV/HCV testing was offered to all people in prison settings, whereas 12 countries (57%) offered testing to prisoners only on the basis of risk factors or for medical reasons. HBV/HCV testing in most countries (71%) was reported to be offered free at the point of use or through reimbursed user fees. Only four (19%) MS reported that non-reimbursed user fee were sometimes charged, but no country reported that this was the only means of accessing testing.

Viral hepatitis cascade of care

For HBV, seven (33%) of the responding countries monitored the numbers of tests, and 15 (71%) monitored the number of positive cases. Four (19%) countries reported available information on the estimated proportion of the chronic HBV population that have not been diagnosed, which ranged from 45% in Scotland (2014) to 55% in France (2004). Seven countries (33%) monitored the number of people treated for HBV. For HCV, eight (38%) countries monitored the number of tests, and 10 (48%) monitored the number of positive cases. Five countries could provide the estimated proportion of the HCV undiagnosed fraction, which ranged from 20% in Denmark (2013) to 78% in Poland (2015). Twelve countries (57%) monitored the number treated for HCV.

Attributable mortality

Six of 22 (27%) countries reported availability of data on at least one indicator of HBV/HCV-attributable mortality: of these, all six reported data available on HBV/HCV-liver cancer, and five

(23%) each on HBV/HCV liver cirrhosis and HBV/HCV chronic liver disease. All remaining countries reported availability of liver-related mortality data, albeit with no information on HBV/HCV status. All countries with HBV- or HCV-specific data reported that data-sharing at a European level might be feasible.

Discussion

The results of this study suggest that sources of information in EU/EEA Member States to monitor the progress towards the EAP milestones and targets related to viral hepatitis diagnosis, cascade of care and attributable mortality are limited. Indeed, a third of responding countries reported conducting no monitoring at all on any of the areas assessed. Among those countries with available data, there was a focus on monitoring some elements of the care cascade (e.g. number of people diagnosed and treated), raising concerns over the extent of the programmatic response to viral hepatitis as recommended by WHO [5]. In addition, some countries indicated that they were either unable, or unaware if it was possible, to share data on mortality related to viral hepatitis with ECDC.

In order to assess programme performance, inform national policy and report on implementation of the WHO strategy and the EAP, EU/EEA Member States will need to build up robust monitoring systems. Currently most EU/EEA Member State are able to monitor notification data on newly diagnosed cases of HBV and HCV. However, heterogeneity of surveillance systems, use of different case definitions and differences in reporting practices across the region hamper the comparability of such data and the quality of these data [9]. Additional sources of monitoring data should include regular seroprevalence and possibly sentinel surveys to determine the undiagnosed fraction, and the fraction of cirrhosis and hepatocellular carcinoma cases attributable to HBV/HCV, as well as the systematic collection of programmatic data related to testing, prevention and treatment coverage. The development of a standardised monitoring framework at the European level, and the mobilisation of political support and commitment at country level to implement it, would provide a robust and explicit basis for ensuring appropriate levels of awareness and resource investment in monitoring activities. Such an initiative could establish standard and routine processes, raise awareness, and influence leverage of the necessary resources, as has been the experience from the European wide monitoring of the Dublin Declaration on HIV that is coordinated by ECDC [10]. The resources required for monitoring and evaluation cost a fraction of the funding currently allocated to viral hepatitis treatments in European countries [11,12], and would yield several benefits, both in raising the profile of viral hepatitis as a significant burden of disease, and in informing policy makers on the most effective allocation of healthcare resources to see real progress in the WHO Global Strategy on viral hepatitis and EAP.

One of the limitations of this study is that it may have failed to capture all available sources of relevant data in EU/EEA Member States as it relied on the background knowledge and expertise of the country respondent. Many respondents reported it challenging to complete the surveys due to the breadth of scope and the need to consult extensively within and between national relevant institutions. While this might have been a valuable exercise at national level, it may have resulted in inaccurate or partial responses [7]. The response rate to both surveys was moderate (approx. 70%), however there was a

geographically representative range of responses from Northern, Southern, and Eastern Europe [7]. Also, only a sub-set of the WHO EAP milestones and targets were covered: for example, monitoring of HBV vaccine coverage, provision of needle and syringe facilities, and facility-level injection safety, were all excluded and might warrant a dedicated assessment.

In conclusion, few EU/EEA countries appear to be ready to monitor progress towards the goals and targets outlined in the WHO Global Health Sector Strategy and EAP on viral hepatitis based on our assessment of available information. Analyses such as that presented here should raise awareness among EU/EEA policy makers and stimulate higher prioritisation of efforts to improve the monitoring of national viral hepatitis programmes.

Acknowledgements

The authors would like to acknowledge the Viral Hepatitis Focal Points in EU/EEA Member States who took the time to respond to the survey, and in particular S Hahne, C Larsen, G Muyldermans, M Rosinska, O Popovici, L Thornton for piloting the survey. The authors would also like to acknowledge the ECDC staff who supported the project, namely A Amato Gauci and C Adhloch.

Conflicts of Interest

The authors have no conflicts of interest to declare.

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